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Children and young people living through a serious family illness: structural, interpersonal and personal perspectives

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Abstract

This study explores the experiences of children and young people in Britain living through a serious family illness. The study considers the interplay between social structures, social relationships and individual agency. We draw on data from the Millennium Cohort Study to estimate the number of children and young people affected nationally and on seven in-depth interviews to understand young people's experiences and the effects on their daily lives. Living through a serious family illness impacts on young people's educational achievements, mental health and social relationships over long periods. Policy and service responses are suggested.

Introduction and background literature

This paper reports on a small funded study that explored the experiences of young people in Britain living through a serious family illness, defined by the charity funding the research as 'when a close family member is diagnosed with a life-threatening illness – such as cancer'. Set against a backdrop analysis in which we indicate for the first time the scale of children and young people in Britain living in such circumstances, the research examined how seven young people experience life when a close family member has a life-threatening illness. The paper feeds into recent debates (Mason and Bessell 2017; Leonard 2015; Nolas 2015) about the interplay between social structures, social relationships and individual agency and asks what type of services and policies might best support children and young people living through serious family health difficulties.

The number of children and young people in Britain living with serious family ill-health is under-researched. Localised studies indicate that a substantial proportion of young people live with someone close to them (parent, carer, grandparent, sibling) who is chronically or terminally ill and suggest that many are unable to access appropriate support to cope with the ensuing difficulties, yet are vulnerable and potentially at risk (Mayall, 2002; Backett-Milburn and Jackson, 2012). Currently, young people experiencing life-threatening family illness in the UK are largely invisible. Rather, studies exploring the impact of young people living with serious family ill-health have often focused on young carers providing care for a family member at home (Aldridge and Becker, 2003), studies of

children with parents suffering from cancer (Kennedy and Lloyd-Williams 2009a and b) or for young people suffering bereavement (Rolls and Payne, 2007; Brewer and Sparkes, 2011; Fredman, 1997). Young people aged between five and fifteen years who had a parent or sibling dying are more likely to experience mental health issues than those who had not (Meltzer *et al.* 2003). Children and young people's experiences of parental substance use within the home (Hill 2015) and the strategies they employ to endure such challenging circumstances are also highlighted (Backett-Milburn and Jackson 2012). Where a child or young person has a life-threatening illness, there are emotional and behavioural problems in 24% of their healthy siblings (Lenton *et al.* 2001), indicating needs beyond the children and young people with the illness.

Relatively little research, however, has explored young people's personal concerns and experiences while living with a serious family illness and its impact on their lives (Backett-Milburn and Jackson, 2012). This reflects the complexity of the field and difficulties in identifying and accessing young people's views and experiences in such sensitive circumstances (Mayall, 2002). A small body of research, however, reveals that young people living with serious family ill-health experience high levels of distress and anxiety (Kennedy and Lloyd Williams, 2009a and b; Backett-Milburn and Jackson, 2012) and are prone to low mood, depression, isolation and self-harming behaviours (Holbrook, 2017).

Few studies have researched children and young people's experiences of living with a serious family illness from the point at which the diagnosis was made. Furthermore, limited research is available to examine the impact that targeted support can have for young people experiencing such challenges. Research in related fields suggests that support in the form of face-to-face and online counselling (King *et al.* 2006) and targeted youth work help young people to endure exceptionally challenging situations (Backett-Milburn and Jackson, 2012) and to develop self-reliant and resilient behaviours (Holbrook, 2017). In summary, the extent and nature of children and young people's experiences when living through a serious family health problem are inadequately documented and responded to patchily.

Theorising personal experiences: individual or social?

Having a close family member with a serious, life-threatening illness seems on the face of it to be an intensely personal and individual experience. Serious illness can strike any family. Its effects on a child or young person within the family will depend on support networks, individual circumstances, previous experiences, personality and reactions to stress. For example, reviews of research into resilience tell of the particularly significant effects of loss of loved ones and of the potentially lasting effects of trauma on children, although the effects are often in the short term (Garmezy 1983, Garmezy & Rutter 1985; Rutter 1983). They emphasise, too, that the availability and support of parents had a distinct impact on children's responses. A focus on an individualised approach to understanding children and young people's experiences of everyday life is central to a significant body of research in Childhood and Youth Studies. Attention to the everyday lives and experiences of children and young people has also been enhanced by their engagement in research (e.g. Children's Research Centre, Open University, and Centre for Children and Young People's Participation, University of Central Lancashire) and their participation in matters affecting their lives (Bradbury-Jones & Taylor, 2015; Kellett, 2010 and 2011; Lundy *et al.* 2011; Prout & James, 1997; Thomas 2007). Underpinned largely by what Nolas (2015 cited in Mason and Bessell 2017:258) refers to as a 'governance approach' to participation, children and young people have become routinely involved

on councils' and organisations' reference groups as a means of having their views accessed, but this tends to maintain established structures and ethos. Children and young people's agency has been foregrounded and their rights facilitated, enabling a focus on their perspectives and seeing them as experts in their own lives, although as Gallacher and Gallagher (2008) point out, not the only experts.

However, an individualised approach to understanding children and young people's lives can lack close examination of 'social' – relational and structural – aspects of experience, which interconnect with and shape children and young people's agency and participation (Mason and Bessell 2017) and can create the illusion of participation without challenging current structural relations (Coppock, 2011). Yet statistically, even with regard to circumstances as seemingly individual as a close family member falling seriously ill and potentially the loss of a parent, sibling or grandparent, there are distinct social structural patterns determining mortality and morbidity (Marmot 2010; Marmot and Bell 2012). Not only does the likelihood of a young person having a close family member with a life-threatening illness vary along socioeconomic lines, so too do risk and resilience factors influencing how likely children and young people are to overcome such difficulties (Schoon and Bynner 2003).

Resilience research points to the promotive and protective factors that mediate children and young people's reactions to adversity including self-control, problem-solving, close caregiver relationships and the quality of schools and community environments. Such factors are 'embedded in individuals, relationships, families, friends, communities, and cultures' (Masten 2001, Masten 2007 cited in Masten and Narayan 2012:232), thus emphasising the inter-relationships between individual and social systems. Similarly, Fattore *et al.* (2017) draw on children's conceptions of wellbeing to reveal how experiences of wellbeing are primarily socially located through intergenerational, social, cultural and political processes. Rogoff's theorisation of human development, too, based on a broad international body of research, considers development to be grounded in participation that should be analysed along community, interpersonal and personal planes. All are intertwined, are always present and should always be considered, whatever the current focus of attention. 'Individuals' efforts and sociocultural institutions and practices are constituted by and constitute each other and thus cannot be defined independently of each other or studied in isolation' (Rogoff *et al.* 1995:45)

The study reported here brings together social (interpersonal and community) and individual (personal) facets of children and young people living with a life-threatening family illness to propose a clearer understanding of policies and services that might best address such circumstances. It:

- analyses national large-scale data to indicate for the first time the likely scale of children and young people living in such circumstances in Britain and the possible impacts (social);
- includes in-depth life-history interviews with children and young people who have not only been affected by such circumstances, but who have subsequently supported other similarly affected children and young people through organisational engagement and actively running services (individual and social/relational);
- is situated within the context of a charitable service that provides relational and individualised support but within a structure run by young people, linked to other agencies, and lobbying for policy change (social and individual).

The study: approach and methods

The study addresses three questions:

- How many children and young people live with a serious family illness in Britain?
- What are the daily life experiences of children and young people living with a life-threatening family illness in Britain?
- What are their support and services experiences?

No research currently evidences the number of children and young people living through a serious, life-threatening family illness in the UK and the nature of their experiences. Addressing that gap, this mixed-method study (Johnson and Onwuegbuzie 2004) drew on three strands of data: first, analysis of aspects of the British Millennium Cohort Study; second, data held in records by a support charity; and third, interviews with a small sample of children and young people. The purpose was to indicate: levels of national need extrapolated from the Millennium Cohort Study; the nature of needs presenting to and service uptake from the charity in the relevant localities; how young people experience living with a life-threatening family illness and the nature of the services they require based on interviews.

Millennium Cohort Study

The Millennium Cohort Study (MCS) is a national longitudinal birth cohort survey tracking children since 2000 through their childhood years and on into adulthood (Centre for Longitudinal Studies, Institute of Education, University College London). The MCS field encompasses parenting, childcare, school choice, child behaviour and cognitive development, child and parental health, parents' employment and education, income and poverty, housing, neighbourhood and residential mobility, and social capital and ethnicity.

We report on one of the main survey elements of the MCS: parent/caregiver self-report data regarding their own health. This provides a picture of how many parents and children may have been affected by a longstanding illness and what it means to live with a family experiencing serious health difficulties.

The MCS sample represents nearly 3% of the population of children aged nine months who were born between specified dates starting in 2000. The two most recent MCS datasets (MCS5 2012 & MCS6 2015; Centre for Longitudinal Studies. Institute of Education. University of London. 2017a and 2017b) were chosen for the purposes of this research because the datasets are open source, are at most only five years old so can be considered recent, contain health survey data on children and their families when the children were aged 11-12 years and again at 14-15 years so are directly relevant to this study, and the sample size for both datasets is substantial (more than 11,000 cases), enabling generalisation to the wider population in the UK.

Individual interviews

A purposive sample of affected young people was selected with the assistance of the support charity. Seven interviews averaging 30 minutes were carried out, three face-to-face and four by telephone at prearranged times to suit the young person. Face-to-face interviews followed 90 minutes during which researchers took part in biscuit-making activities, led by the youth worker, and chatted to the young people, allowing time to establish rapport and gauge approach. Unsurprisingly, many of the interviews were emotionally charged and sometimes tearful. All were audio recorded, transcribed and analysed thematically (Braun and Clarke 2006). The data set comprised over 16,500

words of transcription. A transcription of each interview was sent to the appropriate young person to allow for alterations or additions to be sure we were fully representing their views. Participants included young people aged 16 to 23 years, pertinent given the funding charity's remit to work with children and young people aged 11-25 years. **Appendix 1** outlines the participants' individual and family circumstances. The sample therefore necessarily reflects young people who had sought support from the funding charity and/or have subsequently become volunteers for the charity. Five of the seven lived in Herefordshire or Gloucestershire, one in Lancashire and one other where face-to-face support could not be accessed.

Ethical approval for the interview aspects of the data collection of the study was provided by the authors' HEI Human Research Ethics Committee. Owing to the sensitive nature of the questioning, we sought guidance on how to approach the interviews from the charity, particularly from the youth workers who work with the young people regularly. The interviews took place during routine group sessions with the youth worker present or at prearranged times by telephone, brokered by the youth workers. In advance, young people were given an information sheet with indicative questions so that they felt prepared, could make an informed choice whether or not to participate and could think about how they might respond. Indicative questions were:

- What are the circumstances that brought you to seek support?
- What have your experiences been and how do you think these experiences have impacted on you?
- What you think of the services that are currently available for young people in your circumstances?
- What [other] services you would like to see in place?

The researchers agreed to prompt gently if necessary for experiences regarding home, friends, social life, school/studies, but to be guided by the young people's responses and respect silences.

Information sheets were provided for parents of young people aged under 18 years. Consent to participate was given by the young people verbally, via email and/or via text, as guided by the charity to match their usual ways of working with young people. Each young person was given a pseudonym for anonymity, with the opportunity to choose their own. Pseudonyms are used throughout this article.

Findings

The presentation of our findings is organised as follows. We begin by outlining societal level findings: firstly from the MCS relating to parents/caregivers' health and wellbeing, contextualised by data from the funding charity; secondly with an estimation of the national situation extrapolated from the MCS data and national population data, contextualised by national social patterns of mortality and morbidity. We then move on to present the findings relating to individual experiences, while reflecting on the ways in which these, too, are shaped by social (community or interpersonal) level influences.

Societal level

Data analysed from MCS5 and MCS6 focused on:

- Parents/caregivers reporting on whether they had a long-standing illness, the nature of the illness, and the impact of the illness on their day to day activities.

It should be noted that MCS data do not differentiate longstanding illness from chronic and/or life threatening illnesses, so these are proxy measures for life-threatening illness.

Parents' health

MCS5 (2012) data showed that almost 1 in 5 (n = 4162) of all parents in the sample self-reported that they themselves had a long-standing illness. See Table 1 for frequencies. Of the participants who responded 'Yes' to this question, 50% (n = 2085) said that the illness did have an impact on their own abilities for more than 12 months, and 22.1% (n = 920) said that their illness currently impacted 'a lot' on their ability to do everyday activities.

MCS6 (2015) data showed that this proportion increased from almost 19% to nearly 23% of the sample of parents reporting that they had a long-standing illness. The association between age of cohort member (11 or 14) and reporting of parent long-standing illness (Yes or No) was statistically significant, $\chi^2 (1, N = 40823) = 91.31, p < .0001$. These findings show that cohort members who were 14 were more likely to have a parent with a longstanding illness than cohort members aged 11.

Again, see Table 1 for frequencies. Of those who responded 'Yes', 51.8% (n = 2224) said that the illness had had an impact on their own abilities for more than 12 months, and 23.2% (n = 996) said that their illness impacted 'a lot' on their ability to do everyday activities.

Table 1: Proportion of parents who reported having a longstanding illness – data collected when children in the cohort study were aged 11 (MCS5, 2012) and aged 14 (MCS6, 2015).

	<i>Frequency (%) parents having a longstanding illness</i>	
	<u>Cohort child aged 11</u>	<u>Cohort child aged 14</u>
Yes	4162 (18.9%)	4290 (22.8%)
No	17824 (81.1%)	14547 (77.2%)
Total	21986	18850

Follow up information regarding the nature of longstanding illnesses in both MCS5 and MCS6 for parents show a range of conditions affecting people including stamina/ breathing/fatigue difficulties, mental health issues, diabetes, heart/circulatory problems, neurological disorders, respiratory problems, cancer, kidney problems and multiple sclerosis (these are noted in order of incidence – see Bennett *et al.*, 2018). Referral data from the funding charity since 2010 (Bennett *et al.*, 2018; Payler *et al.*, 2018) shows that 74% of referrals are due to a family member with cancer. Other conditions leading to referral include brain tumour, heart condition, multiple sclerosis, lung transplant, cerebral palsy and Alzheimer's, amongst others.

National picture

Using both the MCS5 and MCS6 data and national population data, we estimated how many children and young people in the UK are potentially living with a serious family health difficulty. The Office of

National Statistics (ONS, 2014) records show that there were nearly 5.1 million young people living in the UK aged 11-17 in 2014 in total. Therefore, it is assumed using MCS5 & MCS6 data that:

- Approximately 20% of all children and young people aged 11-17 have a parent or caregiver who has a longstanding illness, and using ONS figures, then this equates to potentially a million children aged 11 and above in the UK with a parent/caregiver with a longstanding illness.
- Approximately 0.02% of all children and young people aged 11-17 have a parent or caregiver who has cancer, then again using ONS figures, this equates to potentially 10,200 children aged 11 and above in the UK who has a parent/caregiver with cancer.

However, it is clear from morbidity and mortality data for England that health conditions affect different sections of society to varying degrees, with 'steep social gradients' (Marmot *et al.* 2010:52), evident in major causes of ill-health and death such as cancer and circulatory diseases.

Thus, the conditions indicated as causing long-standing illnesses amongst parents or caregivers in the MCS, and those associated with referrals of children and young people to the charity, follow socio-economic patterns. It is clear that the situation in which children and young people find themselves is strongly structured along societal lines. Of nine key messages from the research evidence (European Portal for Action on Health Inequalities 2018), three are relevant here. 1. The lower a person's social position, the worse his or her health, therefore action should focus on reducing the gradient (Key message 2). 2. Reducing health inequalities requires action on six policy objectives: Give every child the best start in life; Enable all children, young people and adults to maximise their capabilities and have control over their lives; Create fair employment and good work for all; Ensure healthy standard of living for all; Create and develop healthy and sustainable places and communities; Strengthen the role and impact of ill-health prevention. (Key message 7). 3. Effective local delivery requires effective participatory decision-making at local level. This can only happen by empowering individuals and local communities. (Key message 9).

In summary, while children and young people experience serious family illness as an intensely personal aspect of their lives, it is clear that the likelihood of facing such difficulties varies according to socio-economic status and is acknowledged as requiring action at the national policy and community levels.

Individual experiences, social influences

Thematic analysis of the interview data revealed that although each young person's experiences were unique as they faced different family health crises and each responded in different ways, there were nonetheless consistent categories discernible across the data (Table 2). Threaded through the young people's stories of their personal experiences were clear references to the ways in which social, structural and procedural aspects of life – of bureaucracies and institutions - shaped those individual stories.

Table 2: Themes and categories from coded interview data

Theme	No. of interview excerpts ascribed to theme
<ul style="list-style-type: none"> • <i>Categories included in theme</i> 	
Experiencing need	42

<ul style="list-style-type: none"> • crises extending across long periods of childhood • young people's understanding of what was happening • experiences of service responses • experiences in daily life 	
Consequences of [un]met need <ul style="list-style-type: none"> • being labelled as 'difficult' • impact on educational experiences and outcomes • impact on social life • feelings of stress and hopelessness 	31
Characteristics of charity support <ul style="list-style-type: none"> • Relationship building • Differentiated support to meet individual needs 	40
Nature of services required by young people: What makes charity support so valued by young people? <ul style="list-style-type: none"> • Flexibility • Acceptance and understanding 	28

In this paper for reasons of space, we focus primarily on the first two of the themes, 'Experiencing need' and the 'Consequences of (un)met need', which shed light on their lives in a family with a life-threatening illness and on the impact of their experiences. The remaining two themes, 'Characteristics of charity support' and 'Nature of services required by young people', related to their perceptions of the charity funding the research and the type of support they wanted from such services.

Experiencing need

Illness patterns, family composition, levels of support available and the young person's emotional responses were all individual, but data in relation to this theme revealed commonalities with regard to: the impact throughout long periods of childhood; young people's understanding of what was happening; their experiences of service responses; and the impact on their daily lives.

Crises extending across long periods of childhood

Whilst the support charity referred to health 'crises', it is apparent from the interview data that these illnesses extended for very long periods across the lives of children and young people and had a tendency to vary in intensity at different times during childhood depending on the trajectory of the illness or condition. This enduring nature of the difficulties meant that they formed a backdrop of anxiety to children and young people's lives, not easily supported by episodic interventions such as counselling. Several of the children and young people described the initial diagnosis being given when they were in primary school and the period of serious illness running throughout their teenage years. Bill, now aged 20 years, reflected for example on the variable nature of living with the illness.

It started at primary school when my mum had breast cancer diagnosed when I was in year 4 and it became terminal when I was in year 9 at age 14. And because it's cancer it has phases so it wasn't like all those years my mum was in a bad condition. There were times when it did get worse (Bill).

Others, such as Brian, explained how the trajectory of illnesses could be complex. Brian's mother was diagnosed with aplastic anaemia and Crohn's disease when he was eight-years-old and she had continuing serious problems over the years, including an amputation. Brian had become a carer for his mother and his younger sister at a very young age. Recently, when Brian was 18-years-old, she had had a stroke.

Young people's understanding of what was happening

Given the young age at which their family members had been diagnosed, the young people explained how difficult it was to understand the situation in which they found themselves and how that shifted through the years.

I didn't really understand what was going on either because I was so young...Just knew that mum wasn't very well and was spending a lot of time at doctors' appointments and stuff. That's all I knew then. (Amy)

Coming to terms with something that they poorly understood was difficult for the young people.

It's confusing and lonely (Emma).

Acknowledging the need for varied and repeated information at age-appropriate levels throughout their childhood was important.

When I started to understand what was wrong with mum, I didn't really understand what MS was, I knew it was a disease that attacks the nervous system, I was like 'she's going to be paralysed, she won't be able to walk. (Amy)

Experiences of service responses

While their experiences of family illness were individual, they were often magnified by the ways in which services such as education, counselling and community youth services responded to their circumstances. Structural inflexibility regarding expectations – real or perceived - for behaviour, school attendance and punctuality, submission of coursework, examination dates and how to respond to a bereavement all created a sense of young people trying to manage in systems that did not fit with their needs, making the systems unmanageable and inaccessible to them. Emma described the inadequate response at school to her bereavement.

Me and another person in my class were going through the exact same thing and I remember when my Mum died when I went back to school and even though they were aware what was going on they took me out the classroom, informed the class and then put me straight back in. It was just completely....well, the teachers just didn't know what to do (Emma).

The apparent lack of training for teachers and their subsequent lack of sensitivity in dealing with such a delicate situation had left a lasting impression on Emma.

My experience that I had been through was such a negative one. There was nothing out of it that was positive at all (Emma).

Amy felt that her behaviour in school had been labelled as challenging and a 'problem', leading to what she perceived as punitive responses rather than understanding and flexibility. But the

alternative of individual counselling pursued by her parents on her behalf had also been characterised by structures and procedures that she could not understand.

They [school] didn't ever try getting help for me. Mum and dad tried, like when I was in primary, I had a counsellor, but I didn't really understand it then either, so I didn't get why I was being taken into a room on my own for an hour to talk about my problems (Amy).

Her trust in counselling was undermined when she discovered that the confidentiality she had been assured of didn't extend to her parents.

I went [to counselling] in primary and was told that everything I told her was confidential and then I went home one day and found letters and that everything I'd been telling her she'd been telling mum and dad. Obviously because I was younger and because of safeguarding and things, she had to do that, but it kind of put me off counselling. She'd told me she wouldn't say anything (Amy).

For Amy, her experiences at school shaped much of her later teenage years.

In the end they had to take me out of education all together and then I calmed down a lot because I wasn't going through stress of school, homework, GCSEs, going to school just to be shouted at, stuff like that. I had a horrible time at school (Amy).

Lisa, too, found the lack of support for someone in her circumstances and lack of flexibility in educational procedures, in her case at university, troubling. As her mother was diagnosed with terminal cancer, she tried to access flexible support.

But even things like ... I tried to go part time at one point and that wasn't an option. My supervisor was great and met with me and tried really hard. And the lecturers were really great but the university system just wasn't set up for it. I then had the decision to... well, do I leave my life and go home for however long Mum's alive for or do I... cos you don't know if it's going to be four years or four months (Lisa).

Lisa's mother's death compounded an existing mental health condition that Lisa had. However, she found that opportunities to maintain contact with her studies and return to her degree in a way she could manage were unavailable.

But at uni if you take a week off cos you're ill then you are completely out of your depth...It really felt like you are kind here all the time or you come back in a year. A year is a really long time because the other thing is if you take a year's leave of absence you are not allowed to live in halls. You are not allowed to use their counselling system. You are not allowed to work in a job – if your job is with them. So when I went on a year's leave of absence I lost my accommodation, my counsellor, my occupation, all in one go, having lost my Mum. It's very cut throat. It made me feel not at all supported by the uni. It wasn't my supervisor, they stayed in touch. It wasn't my counsellor, they stayed in touch. But the only service I was technically allowed to use was the student union's support centre. Cos they weren't under the university (Lisa)

Experiences in daily life

Not all of the young people thought of themselves as young carers, but nonetheless they faced daily routines that were shaped by their close family members' illnesses. Molly described daily life with her mother who has terminal cancer and her grandmother who had had a stroke and who died last year.

When my grandma was alive, I'd have to help sort her out with her breakfast, make sure she took her tablets, help her get up, all that sort of stuff, but then when she got bad, she was bed-bound, so like dad would take mum to dialysis in the morning and I would stay and feed grandma her breakfast. And help sort the carers out, so get all the things ready for them so they could just do their jobs. Then when they'd gone she was under constant supervision as well, so when I wasn't at school I'd be there most of the time just giving her some company and stuff. Making sure at the moment that mum's okay because she's struggling a lot with her memory as well and she's finding things hard. She's on oxygen quite a lot as well as the cancer has spread to her lungs so she can't breathe very well, so I have to do a lot of things for her (Molly).

Typically, young people wanted to protect their family from how upset they were feeling, leading instead to breakdowns once outside the family home and making school harder to endure.

I struggled a lot at school and I started to have massive breakdowns in lessons and stuff. And then my student mentor referred me to [charity]. Before that, I couldn't cope, I'd literally just be crying all the time. I didn't want to cry around family because I wanted to be strong but as soon as I was away from family and with friends or whatever, I just wouldn't be able to hold it together. It was just really difficult (Molly).

Friendships, usually a source of both support and angst during childhood and teenage years, were more difficult to maintain unless the friend shared similar home circumstances.

One of my friends from school, her dad passed away from cancer when we were younger. We were seeing each other at youth centre, but she went to a different school and her dad passed away. She and I got on really well and to this day she's still one of my friends. But most didn't know because I didn't talk about it (Amy).

Consequences of [un]met need

Although some of the young people in the study had received some type of support prior to the charity in the study, they did not feel that it had been of the kind that gave them the help they needed. The consequences of unmet need were categorised as: being labelled as 'difficult'; impact on educational experiences and outcomes; impact on social life; and feelings of stress and hopelessness.

Being labelled as 'difficult'

Not fitting easily into the structures and routines of education led some of the young people to feel that they were labelled as the problem.

I was labelled a problem child. I was sent out of lessons... I literally hate the thought of school now. I left in year 9 and was home educated in the last two years so I have no GCSEs or anything like that (Amy).

Impact on educational experiences and outcomes

Young people reported how far their experiences had influenced the educational opportunities and achievements available to them. Emma, similar to other young people in the same circumstances, found that after her mother had died, being away at university was too difficult.

I went to university to study design and I dropped out. Being away from home affected me in a way I didn't really expect it to. I wasn't expecting to be so homesick (Emma).

Not only did the caring responsibilities have an impact, but the emotional load that came with seeing a person they loved suffering affected their studies.

[R: What about your school work? Did that suffer?] Yeah it did suffer quite a lot because I were really distracted and preoccupied and weren't focusing much either. [R: Did it show in grades? Were you getting behind?] It did show in my grades in exams because we had mocks and the grades weren't very good at all, which impacted me quite badly because I was quite disappointed in them (Lucy).

Amy described how she was 'behind' her peers, but that quickly achieving qualifications was less important than other things in her life.

I had to start at the bottom. I had to do my level 1, then my level 2 and level 3. I've only just finished college now whereas all my friends are in uni and stuff like that. I feel kind of behind, but I also feel like it doesn't really matter (Amy).

Impact on social life

Time constraints as well as the emotional aspects of their situation made it difficult to maintain social lives.

My friends knew everything that was going on with my mum and me being a young carer, but I didn't really have time to speak to them a lot or go out with them and things because I was too busy doing my chores and looking after my family (Lucy).

With a close family member in hospital, visiting routines meant that time outside school and hospital was very short.

And we'd go up and visit [hospital] every day so I wouldn't get much time at home or stuff. So it was straight from school all the way up to Gloucester and stuff, and then come home and then go to bed pretty much (Molly).

Feelings of stress and hopelessness

Unsurprisingly, the young people in the study explained feelings of isolation and hopelessness, that no-one understood their situation and the stress they were enduring.

I know going through school when I was feeling things, they had no understanding at all on how to deal with me or how to deal with the situation or how I was feeling. (Emma)

There was a sense of a being alone in trying to deal with the years of illness following diagnosis.

And the help I received when I went through it was only after the worst had happened. There was nothing leading up to that point (Emma).

Family relationships could become strained as all family members tried to deal with the problems they faced, leading to further feelings of isolation.

Before, at school, me and mum used to fall out a lot, that was why... It used to cause me stress so we used to argue, then me and my dad used to argue. I felt kind of isolated in the family as well. (Amy)

Even with support, the depth of feeling engendered by the circumstances was difficult to cope with.

And it's also really upsetting seeing someone so down in the dumps as well all the time. It's just so...it's just heart-breaking really, seeing her so ill. She just sleeps all day, when she gets back from dialysis, all she does is sleep. She has dialysis four times a week for four hours. But it just absolutely knackers her (Molly).

Each interviewee had a different story to tell of their circumstances and, whilst diverse, all told of profound, emotionally-charged experiences that had impacted on their childhoods and early adulthoods. Furthermore, the qualitative data provides insight into the young people's personal experiences and how these are shaped by social factors and expectations including school attendance, caring responsibilities, behavioural and achievement expectations in educational or service contexts such as schools and counselling services. In summary, while the experience of living through a serious family illness impacts young people individually, reflecting unique personal and family circumstances, evidence indicates that such experiences are further impacted and often exacerbated by broad social factors.

Discussion

The findings of this study highlight the extent to which children and young people affected by family serious illness is at once a societal, interpersonal and personal issue. At the societal level, risk of finding oneself in such a situation is higher for children and young people from lower socioeconomic backgrounds than for those from higher socioeconomic backgrounds (Marmott *et al.* 2010). Exacerbating risks through the 'constellation of factors' involved in social adversity are also higher for those from lower socioeconomic backgrounds, leading to greater risks to academic attainment and a lack of material resources (Schoon and Bynner 2003: 22). However, poor outcomes are by no means inevitable in the face of adversity. Resilience, the 'dynamic process of positive adaptation' to adverse conditions (Schoon and Bynner 2003: 22), builds from promotive and protective factors that enhance the likelihood of a young person managing in the face of such adversity (Masten and Narayan 2012).

At the interpersonal and personal levels, our findings illustrated the complex interrelationships between the promotive and protective factors to which Masten and Narayan (2012) refer such as individual problem-solving, close relationships, quality of school environment or community input. There were also positive aspects to the children and young people's experiences. Since their own experiences, all of the young people interviewed for the study had become involved to some extent

in supporting others who are going through similar circumstances and felt that they had developed empathy which could be used in supporting others. Yet while the participating children and young people are agentive individuals who have gone on to support others, their experiences have been shaped, too, by societal factors, thus recognising the inter-relationship between individual and social systems (Mason and Bessell 2017; Leonard 2015; Nolas 2015). Their experiences were shaped by structural features and in many cases exacerbated by inflexible structures and procedures in institutions, lack of training and understanding amongst people in those institutions and the lack of adequate, timely, sensitive services. In discussion, the young people explained that they needed flexible services that would provide them with a 'safe haven' over long periods of time during varying levels of crisis and remission. Their preferred model of support included gradually developing relationships with like-minded peers and with responsive adults who are 'present' and available, but who would not demand explanation, disclosure or deep conversation. Rather, the safe haven offers a relationally-responsive place around which access to advice, guidance and support to use other services is structured, facilitated by people who understand from experience and with whom the young person has developed a sense of ease, trust and friendship.

There is a national need to identify, recognise and automatically refer for support children and young people who find themselves living through a serious family illness. Age-specific, supportive information in appropriate media for children and young people in such circumstances should be produced and made widely available for each of the most prevalent causes of morbidity and mortality in the UK and to recognise the complex transition from childhood to adulthood where support is often lacking. Alongside, policy at government, local authority and educational institutional level needs to enable flexibility so that such children and young people can retain their educational aspirations, but be offered a 'slow lane' to achieving them, including part-time study so that deadlines, timetables and procedural constraints do not risk pushing them into failure or achievement lower than that of which they are capable. Strategic policy responses need to recognise and respond to the complex interweaving of societal, interpersonal and personal aspects of children and young people living through a life-threatening family illness.

Conclusions

It is evident that children and young people who are living through a life-threatening family illness are largely invisible and potentially constitute a substantial sector of the population. Our research has revealed new evidence to indicate the number affected, the nature of their needs and the impact on their lives. Further, it has highlighted the need for understanding and response at societal as well as personal levels.

Services available to date tend to be geographically patchy, focus on specific categories of need (bereavement, young carers, cancer support charities), are rarely available from the time of diagnosis and on into the long term, or are based around an individualised, standardised model of intervention such as counselling, whether face-to-face, online or by telephone. Children and young people may move through several of these categories at different times during the duration of family illness. When offered, one-to-one counselling is usually given at a set time for a specific period. However, when a child or young person is struggling to cope with their day to day lives and struggling to recognise, articulate and deal with raw emotions while also coping with the pressures of unyielding structures such as school, college and examination timetables, individual counselling can feel too intrusive, inflexible and fail to address the pressures children and young people face.

Findings from our study reveal that young people need services to be available from diagnosis, but that those services need to be based on a flexible model of providing a socially 'safe haven'.

The study highlights the need for social, structural and relational understanding of and responses to the needs of young people in such circumstances. The patterns of morbidity and mortality impacting upon their lives are evident, as are the institutional pressures and inflexibilities that exacerbate their experiences. Such experiences cast long shadows over extended periods of the lives of young people. Yet, responses tend to be individually-focused, inadequately funded, ignore compounding factors and are underpinned by a lack of national data about need, a lack of coherent policy and a lack of strategic service responses. Given the number of children and young people living through a serious family illness and the impact on their daily lives throughout long periods of childhood, a coherent, research-informed national response is long overdue.

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https://www.uclan.ac.uk/research/explore/groups/centre_young_people_participation.php

Appendix 1: Details of interview participants given at the time of interview

Lucy 16-years-old.	Lucy's mother was diagnosed with breast cancer when Lucy was 15 and spent much of last year in hospital undergoing treatment. Although Lucy has older siblings, she is the only young person living at home and she has taken on some of the caring responsibilities. Lucy was diagnosed with depression last October due to the stress and upset of the family health crisis. Her school work has suffered and she has found this very upsetting.
Molly 17-years-old	Molly is an only child. When she was 14-years-old, her mother was diagnosed with stage 3 kidney cancer. Molly's mother spent a lot of time in hospital due to the serious consequences of her illness and was diagnosed as having terminal cancer about a year ago. She currently undergoes dialysis four times a week and is very unwell. About a year ago, Molly's grandmother also had a stroke and became very ill. The family moved to live with her to help care for her. Molly and her father jointly shared the caring responsibilities of Molly's grandmother and her mother. Molly's grandma died last year. Molly is now part of a youth team helping to run the support charity.
Brian 19-years-old.	His mother first became very ill when he was aged 8 years. She developed Crohn's disease and aplastic anaemia as a result of a procedure during a Caesarean section. She has since had an amputation, has been in and out of hospital for years and has had a stroke. Brian took on the bulk of the caring responsibilities from a very young age, caring for his mother, brother and his younger sister who is 7 years his junior. He is now part of a youth team helping to run the support charity as well as working with Young Carers.
Amy 20-years-old	Amy's aunt was diagnosed with multiple sclerosis (MS) when Amy was aged about 10 and, the following year, her mother was also diagnosed with MS. Amy has two older brothers who have helped her through her childhood and teenage years. However, she found the caring responsibilities, school and the uncertainty surrounding her mother's ill health very challenging. She is now part of a youth team helping to run the support charity.
Emma 20-years-old.	Emma's mother died when Emma was in secondary school and Emma found that there was no support for her other than bereavement charities, which didn't help in the run up to the death and didn't meet Emma's needs. She found the inadvertent lack of sensitivity in school in dealing with a young person living through a family health crisis and then bereavement a very negative experience, leading her to volunteer later to work for a support charity.
Bill 20-years-old.	Bill's mother was diagnosed with breast cancer when he was in primary school, aged 9 years. Although the school was sympathetic, there were no local services at that time for him to be referred to. His mother's cancer became terminal and she died when Bill was aged 14 years. Although Bill had the support of family and friends, his mother's struggle with cancer has been a difficult and long part

	of his childhood and adolescence. He is now part of a youth team helping to run the support charity.
Lisa 23-years-old.	Her mother was diagnosed with terminal cancer in 2014 while Lisa was at university. Although Lisa's mother was a medical consultant and felt that there was little need for any additional medical advice and support through, e.g., charities such as Macmillan, Lisa herself needed support but found it difficult to access. She found university procedures unhelpful for a young person living through a family health crisis and subsequent bereavement.